

Programme 59: Pain in the family – young adults I

The experiences of young people whose family is affected by pain and a campaign to help improve their lives

Lost childhood, financial burden, emotional turmoil and guilt – these are some of the challenges facing young people who care for people in pain on top of the caring itself. They're often left feeling invisible, going unrecognised and unsupported for years.

In the first of two programmes putting young carers centre stage, Paul Evans talks to a family about how pain has affected their lives. Erin McGuigan was hospitalised after developing debilitating pain in her limbs and now uses a wheelchair and crutches. She explains how her condition has affected her brother and sisters. Her sister, Donna, talks movingly of her feelings of powerlessness, how she has encouraged Erin, and the need to keep listening and understanding.

Terri Smith a Member of the Scottish Youth Parliament (MSYP), explains why and how she is campaigning to improve the situation for young carers. Hours of freely-given care save the Scottish Government £1.4 billion a year, but often leave young people struggling to stay in education and financially insecure.

Paul Evans: You're listening to ***Airing Pain***, a programme brought to you by Pain Concern, a UK based charity working to help support and inform people living with pain and healthcare professionals.

Chronic or persistent pain has no cure, unmanaged it imposes a huge burden of suffering, devastating the lives, not just of the person with the pain, but the whole family. In this, the first of two programmes funded by The City of Edinburgh Council and NHS (National Health Service) Lothian through their self-directed support innovation fund, I'll be looking at issues faced by the often invisible or forgotten members of those families: the children and siblings of those with pain – their young adult carers.

Erin McGuigan: Because I was the one suffering, he didn't want to draw any attention to himself. You know, everybody was so focused on trying to help me and support me, but maybe he needed more support really.

Terri Smith: Young people are compromising being young people by having caring responsibilities. They save the Scottish Government £1.6 billion annually. Caring shouldn't mean compromise and we should be supporting young carers financially throughout their lives.

Donna McGuigan: When she was in hospital I was there visiting almost every night and I felt like I couldn't do enough, you know, cos I couldn't take the pain away. So I suppose I did have to distance myself a wee bit. It was too hurtful, you know, to be there but not to take the pain away.

Evans: Just some of the burdens faced by young people when chronic pain enters the home. The pain, of course, lost childhood, financial burden, emotional turmoil and, dare I say it, guilt. All at a time when bodies and minds are going through the upheaval of growing into adulthood.

Erin McGuigan has three sisters and one younger brother. She's had chronic pain for around four years, since she was sixteen. I met her at her Edinburgh home with mum Lorna and older sister Donna. This is their story, starting with Erin.

E McGuigan: I just got it, just out of the blue, I was fit and healthy and I was walking one day and suddenly had a pain in my foot and it just developed from there. And then gradually I wasn't able to weight bear on my foot and it was very cold and discoloured and then I had that for a few months and then it spreaded to my left arm as well and then it got worse and spreaded to my right arm. And I was hospitalised for about eight months and I wasn't able to feed myself or get a drink or anything and had to get all care needs met by the nursing staff.

It's affected all aspects of my life really: it affected my education; social life... I use a wheelchair most of the time but sometimes I can manage to walk with crutches but just for short distances, before the pain gets really bad.

Evans: Now some people talk about pain, when pain comes into a family, when somebody in the family has pain, some people talk about it having a ripple effect, like when you throw a stone into a pond and it ripples gently outwards. Has that happened with your family, do you think?

E McGuigan: Yeah, I would say that it's had an effect on all of us. More so on my brother, because he was living at home and a lot of the time we would have to visit hospital at nights – he could wake up and me and my mum aren't there because we've had to take a trip to the hospital, things like that. A lot of the time my mum has to care for me, so she's not got as much time to spend with him because she was caring for me. And emotionally it can be

upsetting seeing family members in pain and not being able to help. Lots of times he has to administer medication to me and he's good and he's understanding but when we went to Bath he had to just live on his own for three weeks really. There's times when we have to go to the hospital and some days he can wake up and we've had to go to the hospital in the night, so it can be lonely for him.

Evans: Mum, the ripple effect, was it a ripple?

Lorna McGuigan: It was a bit of a tsunami [laughter]! I had to take three months off my work to care for Erin initially. And the effect, as she says, on her brother and sisters: we didn't have as much time for them; they didn't know where we were a lot of the time when we were visiting hospitals. Financially as well it had a huge effect: we had to sell our house and adapt this house for Erin's needs. She now has full time care in place, so she has carers in the house, so that in itself has an impact on the other family members and there not as at ease in their own house as they should be.

E McGuigan: It can change your personality a lot and when you're suffering pain you might snap at your family when you don't mean to. You feel frustrated and you might take it out on your family, so it can affect the relationship as well. But in a sense it can also bring your family closer together because you know that you're all there to support each other.

Evans: Donna you're Erin's sister – you've known Erin before the pain – what changes have you noticed in her?

Donna McGuigan: I think she lost a lot of her life. She's not had a normal teenage life. She missed out on a lot of her teenage years. She was always very bubbly, you know and always very energetic. And now she can't do a lot of the things that she could do before. And she was always very, very patient as well – she does suffer from frustration because of her limitations, because of the pain, like she'll be saying she has to pace herself. And sometimes it's understanding that, if you are out or if you are doing things, understanding how she feels and that the pain is impacting her. She could be tired but she holds back, she wants to be involved and make the most of the situation and her life, because that's the kind of person she is.

Evans: She must be very frustrated, but you must be very frustrated as well?

D McGuigan: It is...it's horrible, [crying] nobody deserves that, nobody deserves to go through what she's been through.

Evans: Mum how do you hold the family together?

L McGuigan: Just got to keep going [laughs]! I think it's very hard: when it's an illness that you can see a cure for, you can see a way forward; when you're diagnosed with chronic pain you think this is it for the rest of her life and there didn't seem to be any way forward at that point.

Evans: Donna has obviously told us now of the effect and the effect is coming out now. How have you coped with that?

L McGuigan: Some days I've not! [laughs] Some days we've all struggled to cope with what's happened to Erin, but you just have to keep going, you just have to believe that what you're doing is right. I know sometimes, I've not been there for the other kids – I have another three kids – and I know sometimes I've not been able to support them when they've needed support. And sometimes I've always put Erin first, that's difficult as well as a mother, to know that your other kids maybe need you and you're not able to be there for them, that's hard.

Evans: The Bath Centre for Pain Management Services, part of the Royal National Hospital for Rheumatic Diseases, provides residential pain management programmes for adolescents with chronic pain, like Erin. You can download *Airing Pain* programme 10, from painconcern.org.uk to hear more about it.

Patients attend for three weeks, with an accompanying adult, usually a parent. Erin's mum Lorna again:

L McGuigan: I was determined Erin would get all the help she could get and I pushed and pushed for her to get to go to Bath. I didn't really realise the financial implications of flying down there, being away from home for three weeks at a time; the implications of walking out of your work for three weeks. It is a massive implication on the family, leaving behind your family, leaving your work for three weeks and just walking out the door and concentrating on one child. And using all your savings for flights and taxis... [laughs] that was a huge thing. I think moving forward hopefully people won't have to travel as far in the future and that would be such a good thing, a positive thing.

Evans: Now Erin's had help through the residential pain management programme in Bath, but that still leaves four other children who should get support. Have they had support, other than from you?

L McGuigan: No. Gran and Grandad are very good and they all pull together. We went down to Bath – it's hard leaving your brother and sisters behind. Donna came down for a weekend, Kerry came down for a weekend to spend time with her, but it was very hard on

them. And I was very lucky – lucky is the wrong word – that they were older; I don't know how I would have done it if I'd had younger children. I don't know how I would have coped if I had younger children. But you expect because they're older that they'll just deal with it, but it was hard on them as well.

Evans: Donna, what sort of help do you think you could've had?

D McGuigan: I think it's more understanding the daily battle Erin has to face and understanding the condition. Like my mum said at the time, when she first suffered from chronic pain, nobody knew, the medical profession didn't even know, how she could manage it better. So it's understanding what she's going through. There are times when she needs encouragement, as everybody does, and there are times when she needs to be left just to take it at her own pace, just to take it easy. So it's understanding that to be honest.

Evans: Yes, but you keep on talking about Erin, not about you and your brothers and sisters. What help do young adult carers like you need?

D McGuigan: You're asking the wrong person.

Evans: No, I'm asking the right person.

D McGuigan: Yeah, I suppose at the time when Erin was in hospital, if you were talking to people like your peers or outside of family, they couldn't contemplate what it was we were going through, so I suppose speaking to other people who were going through the same thing would offer comfort and support.

Evan: There are an estimated 100,000 young carers like Donna and her brothers and sisters in Scotland alone, many of whom are selflessly helping others without a thought for themselves. Donna has highlighted the importance of social and peer support. But young adult carers, particularly those in low income families, also face financial barriers. These are issues being addressed by the Scottish Youth Parliament Care Fair Share campaign. Terri Smith is MSYP, that's member of the Scottish Youth Parliament, for Edinburgh and Northern Leith.

Terri Smith: Care Fair Share has got three objectives, the first ones about making the Education Maintenance Allowance... a bit more clarity in the wording that the Scottish Government give guidance to the local authorities, so we are just looking at making that stronger and more clarified, so local authorities implement it as well. Our second objective is about making a bursary available to young carers, to those who are at college or university. The third part is for travel concession, making it more available to young carers, so it's

cheaper 'cos they have to get from A to B, if they're in financial hardship they may find that difficult.

Evans: So, going back to objective one, an Education Maintenance Allowance, what does that mean?

Smith: It's a £30 payment that young people receive every week for attending school or college.

Evans: Now that sounds like a very good thing, but from what I remember the rules for having that were quite strict on attendance?

Smith: Yeah, it requires a hundred per cent attendance for you to receive your EMA payment, which is given fortnightly.

Evans: It seems to me that a young carer can't guarantee a hundred per cent attendance [No] because he or she will have caring duties.

Smith: Of course, sometimes they'll miss the odd class at school, or full day, or even being late for school, again, takes away your hundred per cent attendance, so they're losing that valuable payment.

Evans: That doesn't seem fair does it?

Smith: No it's not fair, especially when it contributes to the household income, which a lot of low income families rely on. 'Cos EMA is given primarily to low income families, so again it's a huge implication on them and it just doesn't seem fair that if they miss the odd day or the odd class, or they're late, that entire payment's gone. It's an invaluable thing to young carers who are struggling financially. A lot of parents rely on the young person getting that money from going to school or college. So when they're losing out on that it's putting more strain on the family themselves and it's not exactly ideal when they've got enough to deal with. So it's like imperative that young people are still getting that money, I think schools should take into consideration, you know, they've got extra needs to the average young person, so it's an invaluable service really.

Evans: Is this something you've addressed with MSPs?

Smith: Yeah, we addressed the clarification of the wording of the guideline documents that the Scottish Government give to local authorities, asked for clarification around the wording of what was required for EMA, and we achieved that, which was objective one of the campaign. So now the MSYPs are being asked to go out and consult with their local

councillors and local authorities and asking them to implement these guidelines. So my job, along with the other eleven Edinburgh MSYPs, will be to speak with the City of Edinburgh Council and urge them to support it and implement them.

Evans: Do you have a long term condition yourself?

Smith: Yeah I do, indeed, yeah. I've got leukaemia. I have all sorts of things, I've got lung problems as well, so it's just something that I've dealt with for the last four or five years.

Evans: So how does that impact on your family?

Smith: I'm fortunate enough that I don't face financial barriers, which I'm thankful for, but the stress upon my younger siblings, it has a knock on effect on them, you know, having to miss going out to their friends during the week because my mum needs someone to look after me, because she can't do it, she has to work. That compromise that they have to make is quite hard hitting, but yeah I see that on a daily basis.

Evans: What do you see?

Smith: My sister is fifteen so she should be out living her life, going out with friends, the same as I did. I didn't have that burden of having to look after older siblings, so I take my hat off to her and every young person that's a young carer.

Evans: What sort of help and support do you think she needs?

Smith: Just that free time to go out and be a young person really, I mean she does lack that support. I don't think she identifies herself as a young carer. I do tell her, you know, you are a young carer, you have caring responsibilities, but she just sees herself as, 'well I'm helping my family'. She sees it as an obligation, yeah...she feels like she needs to do it because I'm her sister. Sometimes I wish she didn't have to do it, but...

Evans: And that sort of responsibility is very much unseen isn't it, people just take it, it's not an obligation to look after your family [no]; it's something that's there and perhaps people outside that family don't realise the help that they need.

Smith: Yeah that's right, her school don't know she's a young carer, a lot of people don't know she's a young carer and that's a problem as well with young carers isn't it? The ones that we know about are self-identified, but there's a lot of carers that no one knows about and again that's an issue in itself.

Evans: Is that something that the Care Fair Share campaign can address?

Smith: I think it's been brought up a few times, particularly when I met with The City of Edinburgh Council, they brought up the issue of how we could identify young carers. We spoke about trying to do it through matriculation and that type of thing, you know identifying them as soon as they come into the education process, whether it be from primary to secondary or up to college, there should be some sort of process for trying to identify more. And letting young carers know what exactly is a young carer because, again they don't know because they perhaps don't have the information to say, well these are the qualities that a young carer has.

Evans: Well that's the thing isn't it? I guess, as we've talked about, most young carers who go into school just don't know they're young carers, so you have to educate them as well.

Smith: Yeah that's true. I mean there's 100,000 young carers in Scotland, so that's ten per cent of the school population and, again, that's the ones we know about.

Evans: The second Care Fair Share objective was looking to get bursaries for young carers?

Smith: Yeah, particularly young carers in college and universities, who don't perhaps come under the EMA guidelines, so like loan payments and stuff, so they're getting a substantial... different amount of bursary. So, again, young carers could qualify as that, they are caring with a responsibility so we're looking to expand on that towards them and giving them that access.

Evans: Might be a strange question because my young days are well behind me: why would a young carer need money?

Smith: Why would a young carer need money? Well to do numerous things, go from A to B, go to appointments with whoever they're caring for – I know my sister, she accompanies me to hospital appointments and sometimes I can't pay her bus fare so she has to pay it herself. But that type of thing you know, going from place to place; supporting the family... again, a lot of young carers I've spoke with, particularly in my constituency, their parents rely on the money they're getting in to support with whether that be the food or different type of things, necessities of life that a lot of young carers rely on the money for.

Evans: When your sister goes with you to hospital appointments, why is she going with you?

Smith: A lot of times I can't go from places on my own, so I need someone to be with me. So she's that support network that I feel like, my parents don't like it but they have to give in and allow it to happen, because there is no one else and we don't want that support from

anyone else, we'd rather it was kept within the family, because it's easier to maintain that way instead of having to bring in other people.

Evans: But support can just mean company.

Smith: She's good at keeping me company that's for sure.

Evans: You're smiling, why are you smiling?

Smith: Because she is, she's great at what she does and it does make me smile.

Evans: Are you close?

Smith: Yeah of course, yeah. She's just always there isn't she?

Evans: Erin, do you understand what your brothers and sisters have been through?

E McGuigan: To an extent, yeah, but sometimes they don't always talk about it because it's easier to just shut it off rather than talk about it. But when you're in pain yourself it's hard to see the people around you and the impact that it's having on them because all you can think about is how dreadful the pain is and sometimes maybe you should make time to look at your brothers and sisters and chat with them and see how it really is affecting them.

Evans: Well family therapists might say that there are two ways that pain in the family impacts on people without pain in the family and one is that it makes them distance themselves from the family, i.e. sends them away from the family and away from the pain; and the other is that it brings them really, really tight in together. Donna, which side do you think you fall on?

D McGuigan: A bit of both to be honest. I've distanced myself and I've been very close to Erin sometimes. I mean when she was in hospital I was there visiting almost every night and it did have an impact on my life and I felt like I couldn't do enough, you know 'cos I couldn't take the pain away. So, I suppose I did have to distance myself a wee bit, it was too hurtful to be there but not to take the pain away and solve the problem.

L McGuigan: I think one of the important messages I got from Bath was that this is not an illness, she's not ill. Whereas I think as a parent you tend to wrap them in blankets and get everything for them, do everything for them till they're better – it's a natural instinct – until they're better and they can do it for themselves. It was accepting that this is a change in lifestyle, she wasn't ill but she had a change in circumstances and we had to learn to cope with it and I had to then take a step back and let her go and let her do things instead of

saying, 'oh, she can't do that she's in a wheelchair'. I had to say, 'she's in a wheelchair – so what! It's up to other people to make it possible for her'. [Laughter] I think that's the big thing.

E McGuigan: You weren't alone in coping with the condition, you were there as a family and it was how you were going to cope as a family, rather than the person coping on their own. And we had lots of sessions where me and my mum were together and before we wouldn't talk about it and I would get frustrated at her and she would get frustrated at me, but one of the main things we got from having the right support was that we were able to open to each other and talk about it. And sometimes it could be upsetting, sometimes it wasn't, but it still always helped us to get it off our chests, how we were feeling and what we thought, rather than just closing in and not talking to each other and discussing it with each other.

Evans: And you followed through the same principles with your brother and sisters?

E McGuigan: Not as much, especially my brother who it probably had the biggest impact on because he was living at home. Rather than draw attention to it, his theory was just trying to take the attention of it and rather than me and him discussing it he always tries to come in and cheer me up and lighten the situation. He doesn't discuss it very much, I feel as though he just sort of dealt with it on his own, very much so him... he closed in and didn't really talk to anybody about it and probably struggled himself rather than talking to people.

But sometimes it's difficult to approach the situation and think how you're going to bring the topic up and discuss it with your family, because I was the one suffering he didn't want to draw any attention to himself. You know, everybody was so focused on trying to help me and support me, but maybe he needed more support really.

Evans: He's too shy to speak to us today.

E McGuigan: Yeah [laugh].

Evans: The third objective of the Care Fair Share campaign by the Scottish Youth Parliament is to do with financial support for travel?

Smith: Yeah, it's about reducing the cost of travel for young carers. I know that if you're in doing a substantial amount of voluntary work and your place of volunteering writes a letter to say that you're volunteering you get reduced travel. So in my eyes, and a lot of the Scottish Parliament's eyes, young carers are volunteers themselves; you know, every year they save the Scottish Government £1.6 billion annually. I think that's a huge figure that sticks in my mind all the time, but again they are effectively volunteer, they're volunteering their time, their service, their love. I understand that it's for their family, but they're doing a huge thing

for society, so undoubtedly I think they should be given that help towards their travel, like my sister who helps me going from one appointment to another, so reducing that financial burden would be a huge, huge thing for young carers in Scotland.

Evans: Do you think it's fair that young carers save the Scottish taxpayer £1.6 billion?

Smith: No, I think it's an injustice. It's a huge amount of money, that sort of money could be used to help to support them in their roles and giving them better financial practices like the campaign is calling for.

Evans: So who in the Scottish Parliament is listening to you?

Smith: I've met with my local MSP, Malcolm Chisholm, he's a huge supporter of the campaign, he's signed our Care Fair Share pledge board. I know other MSYPs have met with their local MSPs in the parliament. I know some people have met with their MP as well, met with councillors, a huge number of parliamentary people as well have met with us and are very supportive of the campaign, yeah.

Evans: And you think you are being taken seriously?

Smith: Undoubtedly we are being taken seriously, yeah.

Evans: Now this Care Fair Share campaign lasts a year, what do you hope to have achieved by the end of the year?

Smith: To make lives of young carers in Scotland better, that's the ultimate goal of the campaign. So whether we achieve one objective or all three I think just bringing the campaign to light, bringing it to people's attention, it being in the media, is doing that again. But, fundamentally, to make young carers' lives better.

Evans: So if I'm looking after the public purse in Scotland, what do I need to know that will send me away and write a cheque?

Smith: Send you away and write a cheque? Young carers save the Scottish Government 1.6 billion annually and ultimately young people are compromising being young people by having caring responsibilities, so by lifting the financial burdens on them, then that's taking away some of the compromise and allowing them to be young people and that's fundamentally what they should be doing. Yes they can care, but yes they can be young people at the same time. Caring shouldn't mean compromise and we should be supporting young carers financially throughout their lives.

Evans: Caring shouldn't mean compromise.

Smith: Yeah that's right.

Evans: That was Terri Smith, Member of the Scottish Youth Parliament, talking about their Care Fair Share campaign. And you'll get more details from their website, which is SYP, that's Scottish Youth Parliament, SYP.org.uk

Now Pain Concern has also launched specific services to support young adult carers, through its forum, where you can connect with your peers, articles in ***Pain Matters*** magazine and information leaflets. All contact details are at our website which is painconcern.org.uk

I have to remind you that whilst Pain Concern believes the information and opinions on ***Airing Pain*** are accurate and sound based on the best judgements available, you should always consult your health professional on any health matter relating to your health and wellbeing. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf.

Don't forget that you can still download all editions of ***Airing Pain***, including number ten about the Bath pain management centre programme for young adults, from the website or you can obtain CD copies direct from Pain Concern.

Continuing our support for young adult carers, the next edition of ***Airing Pain*** will look at how with the right professional support young adult carers and their families cannot just survive, but thrive, when pain is amongst them.

Donna, you're Erin's sister, now you're the expert in this because you've been through it, what advice would you offer to other people?

Evans: Talk and listen to each other and offer compassion when things don't go right and understanding. But I think the most important thing is to talk to the person who is suffering from chronic pain and try and understand their situation and their needs. One of the conversations we did have when she first became ill was when I told her that she will get through it and I never said it will go away or it will get better, or it will... but I told it will get better, it wouldn't always be like this and said it and I made that promise to her, because I know her and I know she would have got through it 'cos I know her character.

Life will never be what it was when she was sixteen, but I think she is gonna be an amazing, amazing woman, based on the experiences that she's had and how she can apply herself. And her life isn't always going to be easy but I do think that she is going to make the most of it and she'll be happy and settled and she'll just be fantastic and I know that about her and I knew that about her then. At that time nobody could have said what her life was going to end

up like, never said she would end up walking again, but deep down I knew she had it in her to pull through and come through to where she is now, and she has.

Evans: Are you a strong family?

D McGuigan: Yeah.

Evans: And do you get on?

D McGuigan: Yeah we do... apart from when we're arguing over hairdryers and make up and clothes [laughter].

Contributors

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- Lorna McGuigan, Erin's mother
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